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ABSTRACT

This issue of "Transition Summary" contains articles about self-determination and becoming a good self-advocate, with each article reflecting the experience of someone who has grown up with a disability. "The Many Facets of Self-Determination" (Michael Ward) discusses the concept of self-determination; offers an historical perspective of the disability rights movement; and outlines the parents' role during the critical stage for self-determination, adolescence. "Who Chooses?" (Bill Mitchell) discusses the need for young people with disabilities to be involved in making decisions that affect their lives, and describes three barriers that restrict their opportunities to learn decision-making: overprotection, low expectations, and lack of stable support systems. "Self-Determination and Normalization among Adolescents: The Family as a Crucible of Values" (Rita Varela) outlines the role of the family in teaching values, the roadblocks facing disabled youth, and the strategies families can follow to overcome them. "Tim Becomes an Eagle Scout" (Bud Fredericks) describes the experience of a boy with Down syndrome who participated in an intergrated Boy Scout troop, earned the rank of Eagle Scout, and spoke about his handicap at school assemblies. Concluding the document are suggestions for parents on helping children achieve self-determination, a brief bibliography, and a list of organizations. (JDD)

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TRANSITION SUMMARY

National Information Center for Children and Youth with Handicaps

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SELF-DETERMINATION

The purpose of this issue of *Transition Summary* is to acquaint readers with the issues of independence and self-sufficiency -- sometimes called self-determination or self-advocacy -- that young adults with disabilities face as they look toward the future. In this issue, we also offer parents guidelines, insight, and practical advice on helping their children with disabilities cultivate some of the skills they will need to function more independently as adults.

People with disabilities have diverse needs and abilities. Someone with a physical disability may have different needs from someone with mental retardation; likewise, someone with learning disabilities may have needs that differ greatly from someone with an emotional disturbance. In spite of this diversity, however, most people with disabilities have this in common: they can express their own viewpoints, and can make informed decisions about matters that affect every aspect of their lives.

This *Transition Summary* does not attempt to present the diverse needs of people in different disability groups or the needs specific to any particular disability group. Instead, the focus is on the need for young people with disabilities to take charge of their own lives and to speak for themselves in an effort to overcome discrimination, segregation, and unequal opportunities based on disability. Also discussed are the rights and needs of these individuals to live with dignity and respect; to have the same opportunities to fail and to succeed as people without disabilities; and to no longer be seen as individuals perpetually dependent on welfare and charity.

In most families, an adolescent's transition to adulthood is a stressful period. For families with children who have disabilities, the transition may be even more disruptive. The forms that the stresses may take and the ability to react to those stresses will vary from family to family, depending on the number of family members, the family's geographical location, their social and financial resources, and their personal values and beliefs (Brotherson et al., 1986).

For parents, the period of transition means learning how to gradually let go, becoming less protective, and fostering in their child a sense of self-assurance, self-reliance, and responsibility. For many young adults, transition means leaving school and/or home, and undergoing personal change as well as changes in their relationship with their parents. It means having more independence and more responsibility.

Recently, people with disabilities have begun to consider themselves a minority group denied basic rights, such as attending public schools, becoming employed, marrying, and bearing children (Funk, 1987). Indeed, only in the past two decades have many rights and freedoms -- taken for granted by nondisabled persons -- been made available to people with disabilities. According to a recently conducted nationwide survey of 1,000 disabled people, "there are clear signs of an emerging group consciousness among disabled persons" (*The ICD Survey of Disabled Americans*, 1986).

Today, the focus of civil rights legislation for individuals with disabilities is "to assist individual disabled people to achieve a normal life experience as a citizen, not to create a nearly normal person as has been the focus of human service providers" (Funk, 1987). Along with the need to be recognized as people with their own rights, there is a call to reconsider the ways in which society thinks about and treats disability and the disabled. According to Thomas (1982), "One of the failures of our society is...its [inability] to comprehend the normality of handicap. It is the overwhelming insistence that we perceive and encourage 'the disabled' to perceive themselves as deviant that is the root of the problem." Thomas further observes that cultural attitudes toward those with disabilities have progressed through three stages: in the first, the person with a disability was considered helpless; in the second phase, skilled professionals became involved in "helping" those with disabilities; and in the third stage, persons with disabilities exhibit determination and question their roles as passive recipients of help (Thomas, 1982).

According to Gartner and Joe (1987), what is needed in education and other human service fields is "a recognition of the range of humankind, the awareness that all individuals possess both strengths and limitations, in varying mixtures and to different degrees." This requires that we avoid the use of terms and language that either deny the fact of the disability or that dispel reality. "Being disabled is not a 'challenge'... [the disabled] ... voluntarily undertake. Nor is it that we are merely 'differently abled.' We are disabled; there are just some things we can't do, at least not as quickly or as easily as other people" (Browne et al., cited in Gartner and Joe, 1987).

This issue of Transition Summary *contains articles about self-determination and becoming a good self-advocate. Ironically, much that has been written about these subjects has come from professionals rather than from people with disabilities. Each of the articles in this publication, however, reflect the experience of someone who has grown up with a disability.*

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THE MANY FACETS OF SELF-DETERMINATION

by Michael J. Ward

In the article that follows, the author describes his concept of self-determination and discusses parents' roles in encouraging their children with disabilities to trust and respect themselves, to gain self-assurance, and to become as independent as possible.

Michael Ward is the Chief of the Secondary Education and Transition Services Branch at the Office of Special Education Programs, the U. S. Department of Education. Before holding this position, he was a rehabilitation counselor for adults with developmental disabilities in Brooklyn, New York.

He grew up in Brooklyn, where he attended public schools. Recently, he completed a Ph. D. in Special Education at the University of Maryland.

Dr. Ward has cerebral palsy and uses a wheelchair.

What is Self-Determination?

Self-determination has been defined in a variety of ways. The *American Heritage Dictionary* (1976), defines it as "the determination of one's own fate or course of action without compulsion: free will." Another source defines it as "decision according to one's own mind and will" (*Webster's New World Dictionary*, 1972). A common element in both definitions is the importance of people taking control, without undue external influence, over what affects their lives.

Self-determination refers both to the attitudes which lead people to define goals for themselves and to their ability to take the initiative to achieve those goals. Acquiring the personal characteristics which lead to self-determination is a developmental process that begins in early childhood and continues throughout adult life. While it is important for all people to acquire these traits, it is a critical -- and often more difficult -- goal for people with disabilities. They must first shatter the pervasive stereotypes which imply that they cannot, or perhaps should not, practice self-determination.

The traits underlying self-determination include self-actualization, assertiveness, creativity, pride, and self-advocacy. The terms "self-actualization" and "assertiveness," borrowed from modern psychology, are important in the development and personal growth of all individuals. Self-actualization refers to realizing your potential and living your life accordingly. Assertiveness is being able to express your needs clearly and directly and to act and speak out with self-confidence (Des Jardins, 1986). Creativity is the ability to be innovative; to move beyond stereotyped images and expectations. Pride in yourself and your abilities is a trait that translates into feeling good about the contributions you can make to society. Self-advocacy, an essential component of self-determination, refers to the ablility to act on your own behalf. This concept is an outgrowth of the grass-roots disability movement of the last 20 years, a movement which has given disabled people the right and power to take necessary, but often unpopular, actions to ensure that their basic civil rights and social and economic needs are addressed. For people with disabilities, self-advocacy is "running risks, challenging rules, and acquiring resources" (Varela, 1986). It also involves "knowing your basic human rights; standing up for your rights; taking responsibility for your life; and asking for help because you want it or need it" (McGill, 1978).

Achieving self-determination, to borrow a concept from Gestalt psychology, is definitely "more than the sum of its parts." It requires not only that people with disabilities develop inner resources, but that society support and respond to these people. Self-determination is a lifelong interplay between the individual and society, in which the individual accepts risk-taking as a fact of life and in which society, in turn, bases an individual's worth on ability, not disability.

Persons with disabilities who want to achieve self-determination need to learn how to trust and respect themselves. They also need to learn to identify their rights and needs and to find the most appropriate ways of communicating these to others. But most importantly, people with disabilities must acquire a sense of political purpose and an understanding of their rights, responsibilities, and the democratic process (Williams and Shoultz, 1984).

Historical Perspective of the Disability Rights Movement

For centuries, society as a whole treated people with disabilities as objects of pity and fear. They were viewed as incapable of participating in or contributing to society. Prior to the 20th century, societal attitudes reflected the view that persons with disabilities were "unhealthy, defective, and deviant," requiring "special institutions, services, care, and attention in order to survive" (Funk, 1987). The national policy that grew out of such attitudes emphasized the reliance of people with disabilities on welfare and charitable organizations.

Even today, many people assume that children with disabilities are segregated from non-disabled peers because they cannot learn or because they need special help or protection. Similarly, for many, the absence of people with disabilities in the workforce is obvious proof that such people cannot work. Little thought is given to the idea that people with disabilities, in fact, are discriminated against (Funk, 1987).

Despite efforts through public policy in the 1950's and early 1960's to integrate persons with disabilities into community programs, societal attitudes had an isolating effect on persons with disabilities, forcing them to identify with and participate in groups of their own kind. Goffman (1963) wrote in the classic work in disabilities literature, *Stigma: Notes on the Management of Spoiled Identity*, that the relationship of such people to informal and formal community organizations made up of their own kind is crucial to the self-concepts of group members. However, his book was written long before it was recognized that persons with disabilities could use these organizations to improve their social status, and thus reduce the stigmatizing effects of segregation and isolation. The social and political climate of the civil rights re-

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form movement of the 1960's greatly influenced the disability rights movement. The role of people with disabilities shifted from passive dependence to active involvement. Rather than being recipients of philanthropy, they were becoming active participants in a far-reaching civil rights movement that challenged the stigmas associated with other minority groups, as well, such as ethnic minorities, women, gays, and the elderly. This shift in attitude raised the consciousness of these groups to the point where "the minority group is no longer one for whom pleas, reforms and changes are made by others, but where they themselves [those in the movement] are instrumental in provoking change" (Thomas, 1982). People with disabilities began to understand that, among their rights, they had freedom of choice and freedom to belong to and take part in society (Funk, 1987).

Along with the civil rights movement of the 1960's, local independent living centers emerged across the country. Weiner (1986) defines an independent living center as "a community-based program that has substantial disabled citizens' involvement and leadership and provides directly, or coordinates indirectly through referral, those services necessary to assist disabled individuals to increase self-determination and to minimize dependence." One of the first such centers was the Center for Independent Living, established in 1964 at the University of California at Berkeley. Its impact was far-reaching. Not only did it provide a wide range of services to the community it served, it was created by people with disabilities to meet their needs as they saw them. Thus, it became the symbol of all that those with disabilities could achieve, given the chance, and gave momentum and credibility to the independent living movement and the concept of self-determination.

The acquiring of self-determination is not limited to persons with physical disabilities. People First and United Together are two disability consumer organizations made up of people with mental retardation and their aides.[1] These organizations offer evidence that although it is often difficult for people with mental retardation to express their needs clearly, they can learn to manage an advocacy organization (with help), and can make decisions that affect their lives. Self-advocacy cannot be reserved for the "elite" among individuals with disabilities. People with mental handicaps who cannot communicate well can and should be encouraged to contribute in self-advocacy groups. With time and help, they, too, can learn the skills they need to participate in issues that affect their lives.

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Adolescence: The Critical Stage for Self-Determination

Manus and Manus (1983) discuss the theory that adolescence is a phase in which young adults, both with and without disabilities, test their own knowledge, try out new roles, and rely on peer groups, rather than their families, for support. Generally, it is a phase in which young people challenge parental authority in order to assert independence and gain control over their lives as a necessary part of successfully moving into adulthood.

Many young people with disabilities have difficulty with this process of transition for several reasons. First, it is difficult for adolescents to be independent psychologically and emotionally from their parents when they are dependent on them for meeting their basic physical needs. Second, although adolescents without disabilities may encourage and reinforce the expression of differences, a disability may be a difference that they find unaceptable.

Some of the barriers that young adults with disabilities face are in fact found within the family structure. A major obstacle is not being given the right to fail. All adolescents must be allowed to "absorb the pain of failure, to react immediately to failure or to delay and react to failure later" (Manus and Manus, 1983). As children with disabilities become older, they should be given more responsibilities and the support they need to make their own decisions, even when parents feel that such decisions are not the best ones. Young people with disabilities need to learn that it is all right to fail and start over again. Failure can provide important opportunities for problem solving, decision making, and responding creatively to difficult situations. By being allowed to fail and to make mistakes, young people with disabilities can begin to develop an understanding of their abilities and limitations.

Parents and other adults can do much to encourage children with disabilities to exercise independence and self-determination. For example, children need to be included in making decisions that affect the whole family, such as where the next family outing will be, what the next family car will be, or how family time will be spent. As early as possible, children should make decisions about basic issues that directly affect them -- what clothes they wear, for example, or how their bedroom furniture is arranged.

Parents should also encourage their children to perform household chores that are within their capabilities. It has been said that parents should never do anything for their children that their children can do for themselves. This is especially sound advice for parents reluctant to assign chores or responsibilities to their child with disabilities in the belief that he or she is already overwhelmed and should avoid anything that would make life more difficult. While doing chores may take longer for some people with disabilities, most are not in any overwhelming physical discomfort. Chances are that children who grow to feel overwhelmed by their disabilities may have been treated as "special" or "sick" by parents, siblings, teachers, friends, or relatives.

An important point for parents to remember is that children challenge their parents in a sincere and necessary attempt to become independent adults. For young people with disabilities, this conflict may be more difficult or prolonged, but it is just as necessary as it is for all young adults.

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[1]The aides in these organizations are non-handicapped helpers who provide support and assistance with the development of ideas, but who do not function as leaders in the organization (Williams and Shoultz, 1982).

WHO CHOOSES?

by Bill Mitchell

Parents are a strong, stablizing force in a child's life and play an important role in helping the child develop self-confidence and a sense of independence. Parents of a child with disabilities typically want to protect the child, an instinct based primarily -- but not exclusively -- on a realistic knowledge of the child's limitations.

In the article that follows, the author discusses the need for young people with disabilities to be involved, as much as possible, in making decisions that affect their lives. He also discusses ways in which families affect their child's ability to take risks, make decisions, and live with the consequences.

Bill Mitchell works in the Governmental Affairs Office of the Association for Retarded Citizens (ARC) in Washington, D.C.. Currently, he is involved in a project funded by the Department of Housing and Urban Development to provide technical assistance in the finance and design of housing for people with disabilities.

He came to Washington on a fellowship with the National Council on the Handicapped, during which time he wrote a paper on developing leadership in the disability rights movement.

Mr. Mitchell grew up in Atlanta, Georgia, where he attended public schools. He later graduated from Georgia State University with a Bachelors degree in Philosophy. Before coming to Washington, he worked as a counselor for students with disabilities at Georgia State University and as the staff advocate for the Georgia Advocacy Office.

Mr. Mitchell has a mobility impairment.

Historically, people with disabilities, both individually and in groups, have had few opportunities to exercise choices in their lives. In his book, *From Good Will to Civil Rights: Transforming Federal Disability Policy* (1984), Richard Scotch observes that "disabled people generally have not spoken for themselves, and public policies have typically dealt with their needs in ways shaped by stereotypes of dependency."

The lack of involvement of people with disabilities in decision-making at the policy level has its roots in the lack of participation in decision-making at the individual level. Decisions affecting people with disabilities have frequently been made by others. Those disabled early in life have gone from having parents make decisions for them to having doctors, social workers, or rehabilitation counselors make decisions for them. Those raised in segregated facilities have found their chances of making their own decisions restricted even further. No wonder then, that when confronted repeatedly with the message that they must learn to take responsibility, many people with disabilities feel confused and unprepared.

What are the barriers to exercising choices? Based on my observations and experiences with other people with disabilities, I have identified three barriers that I believe restrict opportunities for young people with disabilities to learn to make their own decisions:

1. Overprotection

Ironically, those who care most about individuals with disabilities may be among the obstacles to their gaining the experiences necessary to exert more control over their lives. Typically, most parents, but particularly parents of children with disabilities, feel the need to protect their children from the pain of failure and rejection. Yet, as they mature, children will be exposed to situations that require them to make choices and abide by the consequences.

As a part of growing up, youngsters will be out in their environment -- "hanging out" with the neighborhood kids, exploring the woods beyond the back yard, or stopping at the corner store on the way home from school -- out from under the watchful eye of a parent or other authority figure. It is during these times that children begin to learn more about their own capabilities and limitations and to feel a sense of autonomy.

In some cases, the combined effect of parental concern and environmental barriers may lead to a situation in which a child with a disability is never out of the house unless in the presence of a parent or another adult. The natural tendency of parents to protect their children is reinforced by the reality of the difficulties present in the immediate environment. Parents of children with disabilities often do not have a basis of comparison for determining what are acceptable versus unacceptable risks in the environment, and consequently may lack the reassurance needed to be able to allow their children their own "space" to find their way in the world.

In my own experience as a child having a mobility impairment and using a wheelchair, I got out a lot, explored my surroundings, and played with the neighborhood kids. These unsupervised experiences were among the most important in my life. I learned about relationships and about taking responsibility for my own actions, and generally broadened my perceptions of the world around me and how I fit into it.

Compare my experiences to those of a child in a residential facility. One situation reflects the society we live in -- the real world; the other reflects a society limited by restrictions that skew the child's perception of the world. When I consider my experiences of growing up in my own community and attending a neighborhood school where I had the same restrictions as other children, and then compare them to the experiences of acquaintances who have spent a significant part of their lives in residential facilities, it is not hard to account for the uncertainty many of them feel when confronted with challenges and opportunities.

Unfortunately, for many adults with disabilities, decisions to take on new experiences are influenced more by the degree of risk involved rather than the opportunities afforded by the experiences. And while my observations are unscientific, there seems to be a direct correlation between the degree of restriction these adults had as children and their fear of taking risks as adults. If you have been told much of your life that there are so many things that are too hazardous for you to do, and if you have never been given the opportunity to test the true limits of your capabilities, it wouldn't be surprising that you would be obsessed with security.

2. Low Expectations

Another barrier to the achievement of self-determination for many people with disabilities involves the low expectations that society has of them and consequently, that they have of themselves. As people with disabilities, we receive conflicting messages from different sources telling us: (1) that we are absolutely incredible for doing the most trivial of things; and (2) that whenever non-disabled people are around, we should let them help us do whatever we are doing because, surely, they can do it better. Instead of being encouraged to challenge ourselves to the point that we run a real possibility of failure, every effort is made to ensure that this doesn't happen. In the process, we are denied the thrill of a hard-earned success.

Such negative messages about the capabilities of young people with disabilities can be countered by conscious efforts on the part of parents or other adults. As I was growing up, and to my complete consternation at the time, I was constantly challenged by my parents about whether I actually had done my best at different tasks. They attributed neither my successes nor my failures to my disability. In spite of what they may have felt inwardly, they never allowed me to feel that merely "getting by" was good enough. While psychologists may debate the effects of such an upbringing on the young psyche, it did lead me to expect more of myself. Being challenged in this way also regularly required me to make choices for myself: I chose either to keep working at something to make it better, or I chose to declare the deed done.

The importance of receiving the message that those who care about you have faith in your ability not only to succeed, but also to survive failure, cannot be overstated. Having a "good" failure is something everyone should experience. To know that it is a normal part of life and that people still care about you and believe in you can encourage you to get up and try again. Another effect of this kind of early learning is a sense of feeling more in control of your own destiny.

The more significant a person's disability is perceived to be, the more urgent it is that he or she be given every opportunity to exercise choices. Whether children with disabilities indicate their decisions through verbal communication, or with the aid of a pointer, a micro switch, or a communication board, it is important that they exercise the right to make choices, and in matters in which they can see the effects of their decisions.

The importance of receiving the message that those who care about you have faith in your ability not only to succeed, but also to survive failure, cannot be overstated.

3. Lack of Stable Support Systems

The lack of basic support systems to help one cope with failure can be particularly difficult for persons with disabilities. Discontinuity in some of the basic necessities of life, such as home, community, or friends, especially during the formative years, can add an additional barrier to the disabled person's freedom to make autonomous choices. In some cases, the person's need for security and safety in the environment may outweigh the benefits of assuming a new role in the community or taking on a new job that might further his or her career. While it may seem contradictory to the earlier point about overprotection, having a sense of belonging and a feeling of continuity in your environment is an important element in being able to challenge your capabilities. To be comfortable in taking risks, it helps to know that you've got a place to come home to after it's all over.

For parents, this means trying to provide stability and security for your children with disabilities to the greatest extent possible, while also giving them the freedom to explore. I believe that young adults with disabilities who are beginning to cope with increasing responsibilities and who are feeling overwhelmed by their choices can ease their anxiety by looking for small ways to bring stability to their world. For example, I love Mexican food, so at least once a week, even if the walls are crumbling around me, I go to the same familiar restaurant where they know me by name and always seem glad to see me. A small detail, perhaps, but it helps me gain perspective when other things are in flux. No matter how unstable an individuals's circumstances may be, being able to find even one small "island of calm" that provides an anchor can do wonders for one's sense of stability.

I have listed three basic obstacles that young people with disabilities face as they strive to become adults with the confidence in their own capabilities necessary for exercising self-determination. All three barriers have the potential to limit opportunities in making choices. Parents can help their children to overcome these barriers by providing as many opportunities as possible that allow their children to take prudent risks and make decisions independently.

As I see it, there are two challenges to be addressed:

- How to expose children with disabilities to more opportunities to make choices for themselves and to deal with the consequences of their choices; and
- How to support and encourage young adults with disabilities as they explore their capabilities and options.

The answers that parents and other caregivers come up with today to these questions will determine the degree to which the next generation of young adults with disabilities is prepared to meet the challenges of a changing world.

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SELF-DETERMINATION AND NORMALIZATION AMONG ADOLESCENTS:
The Family as a Crucible of Values

by Rita A. Varela

Parents play an important role in teaching their children decision-making and problem-solving skills. The family can be viewed as a "training ground" where members learn how to adjust to feedback from others, how to make decisions, and how to receive guidance in what is expected of them (Summers, 1986).

In the article that follows, the author discusses the family as a source of values and support.

Since 1983, Ms. Varela has worked as a programmer analyst for GTE Data Services in Tampa, Florida. Her latest breakthrough is a book on statistical analysis, Victory Over Statistics, targeted to mid-level managers, MBA students, and grant writers. Before coming to GTE Data Services, Ms. Varela was a project coordinator for the American Coalition of Citizens with Disabilities in Washington, D.C.

She was born and raised in New York City, where she attended public school, and received her undergraduate degree at City College of New York. She has an M.A. from New York University and is working on an M.B.A. from the University of Tampa.

Ms. Varela has cerebral palsy.

Introduction

When I think about the term "self-determination," the overriding issue that comes to mind is the question of how to live your life in such a way as to actualize its full potential. I also associate the term with my days as a graduate student in political science, when the need to make a living and pay the rent was far from my thoughts and the diaries of libertarians such as John Stuart Mill and Henry David Thoreau absorbed me.

"Self-determination" is not a term I generally associate with rehabilitation literature. Yet, clearly, the term touches on two areas which are crucial to understanding both adolescents and disability: first, the role of the family as a crucible of values; second, the roadblocks facing disabled youth and the strategies families can follow to overcome them.

The Family as a Crucible of Values

Many authors have portrayed the family as a crucible of values from which we learn about winning, losing, cooperation, and conflict. I subscribe to this view with joy and fervor.

It was from my family that I first learned about planning, persuasion, and money. I don't remember when I did not know that a nickel was worth more than a penney, a quarter was worth more than a dime, and paper money was what you saved in the bank so that you could buy a house on Long Island. As for planning and persuasion, I still remember the arguments I had with my folks whenever I wanted to go downtown by myself. I grew up in New York City and was unable to use public transportation, so before I asked permission to go anywhere, I would go through the long, drawn-out process of calling a van service, negotiating over a day, a time, and a price, and investigating all the other details I had to memorize in order to prove to Mom that I could be trusted to take charge of my destiny. As I look back on those days and the hazards of urban life, I realize that the most extraordinary part of the arguments was that I won them.

To an adolescent, self-determination means the power to run your life your way. It means the right to make all the choices that adults in society can make. Before we dismiss this definition as simplistic, let me suggest that it has one virtue: namely, it mirrors the experience of transition from adolescence to adulthood. Though cynics may quip that parents won't stop telling their children what to do until they reach the age when they forget who their children are, parents do let go. The torch -- which in this case is the power of young adults with disabilities to make choices that once were made for them -- is indeed passed in the vast majority of cases. With that torch come lessons. Planning, persuasion, and introductory economics involve basic cultural and political information transferred from parent to child so early that we rarely identify when a child begins to scheme, negotiate, or barter. This transfer nearly defines traditional parenting.

Roadblocks and Remedies

The motivation underlying this transfer is empowerment. Parents want their child to enter the world of adulthood on an equal footing with all other adults. People with disabilities, however, often face roadblocks to full equality. Many roadblocks are institutional. Others stem from personal conflicts over values and identity which invariably befuddle adolescents.

All advocates know about the institutional roadblocks. We've all heard about parents who fight to get their child in school, who literally beg to get a dentist to treat their child, or who spend hours on the phone tracking down reliable transportation. The remedy for these roadblocks is equally clear: parent advocacy -- which means fighting, fighting, and more fighting. Personal roadblocks, however, are more complex.

A persistant sore faced by youth with disabilities concerns the problem of putting disability in perspective. Where does the disability end and the "you" begin? When things happen to you that you don't like, how much can be ascribed to you as a person and how much to your disability? Most kids with disabilities feel they are overprotected. So do most nondisabled kids. The difference is that in the former case, the kid is plagued by the thought, "If I weren't disabled, would it be different?"

Parent-child conflicts are a fact of life, not just a fact of disability life. Children with disabilities need to know that. They need to learn how the world works, how authority is transferred from parent to child, and how to get around obstacles. One of the best things parents can do to teach their children about the world is to widen the family's social circle. Though socializing is not always seen as either a priority or a simple matter by the parents of a child with a disability, teenagers with disabilities should see how other teenagers deal with their own conflicts with parents. Some teenagers with disabilities will conclude that the grass is greener in the next yard; others will not. In any event, a child can learn a lot by watching other children elbowing their way through adolescence. Parenthetically, watching other parents deal with teenagers can be instructive to grown-ups, as well.

An issue related to families and values concerns therapy on the homefront. More specifically, it involves the danger of parents becoming too focused on rehabilitating their child. Though I can't prove it scientifically, I firmly believe that the quality of your ethics, or, more precisely, the amount of time devoted to examining your ethical assumptions, bears directly on the quality of your life. I believe, for example, that all children should be taught it is wrong to steal apples. I do not feel that you should skip teaching this if your child hates apples or if your child is severely spastic, in a wheelchair, and unable to "reach" for an apple.

Though I do not advise parents to refuse to do therapy at home, I do suggest that parents set limits. The home must remain a home, not a rehab center. In that home, all children should be treated as future citizens, not as patients. And in that home, if a choice must be made between administering therapy and taking time to explain why it is wrong to steal, I urge the latter.

Summing Up

Perhaps the quintessential portrait of the family as a crucible of values occurs in *The Autobiography of John Stuart Mill* (1964). Mill describes taking long walks with his father and discussing famous books. His father used these occasions to offer "explanations and ideas respecting civilization, government [and] morality" (Mill, p. 29). That portrait sums up my view of what politics is all about, as well as my views of parenting at its best.

Self-determination? It means the right to make the kinds of choices that others have a right to make, and it requires equal access to public institutions. Parent advocacy? Parent advocates are the first in battle, tackling roadblocks which threaten a child's chances to participate in society and compete on an equal footing. The family? That's where you learn to plan and fight and scheme and dream about being the President of the United States. When you are a clumsy, sweaty, five-year-old, no one on earth will share those dreams with you except, possibly, your parents.

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Parent-child conflicts are a fact of life, not just a fact of disability life.

ANGER IN YOUNG ADULTS WITH DISABILITIES

Society often does not allow an individual to forget his or her disability. As a result, many young people with disabilities feel frustrated and angry.

The section that follows is taken from a letter written by a young man to a counselor who expressed concern over a 7-year-old client's anger at having cerebral palsy. The author of the letter, who has cerebral palsy, is presently studying to be a lawyer.

Dear _____,

...I would like to add my own observations based on my perspective as an adult with cerebral palsy who was once an angry 7-year-old. When you stop to think of it, the anger the child feels is not unreasonable. Adults tend to overlook the fact that being able to walk and talk properly is much more important to a 7-year-old's satisfaction with life than it is for an adult. It may seem very unfair to the child to have been singled out for this problem. Furthermore, the adults around the child seem powerless to correct the problem.

Indeed, the child's anger may be a reflection of the disappointment that the adults around feel. The anger may be self-directed. I'm guessing at this child's feelings, based on my own experience and those of other people I have known who have this condition. The important thing is that the anger is interfering with the child's development.

In your letter [to me], you talk about teaching the child to accept the disability. Frankly, I think the notion of acceptance is overrated. Many of the people I know who have cerebral palsy and who have succeeded in becoming independent and contributing members of society are quietly angry. The difference is that they've learned to use their anger in constructive ways.

Your priority challenge as a counselor may be to help this child channel the anger away from self and others and toward the challenges presented by the disability. It may help the child to know more about cerebral palsy and about people with cerebral palsy.

It's important that the child knows that there are people in this world who have as much and more difficulty with walking and still manage to lead satisfying lives. It would be even better if the child could meet some adults with cerebral palsy who are living in the community, and learn more about the activities that people with disabilities can enjoy (J. Murphy, [personal communication], June, 1987).

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TIM BECOMES AN EAGLE SCOUT

by Bud Fredericks

Having role models may be one way to dissipate some of the frustration, anxiety, anger, and lonliness that many young adults with disabilities feel. Role models need not be superheroes, but rather people with disabilities who have accomplished goals that are important to them.

The article that follows describes a young man whose determination has led him to realize personal aspirations that many people never attain -- a strong sense of dignity and self-worth.

The author of this article, Bud Fredericks, is a research professor at the University of Oregon in Monmouth. He is the father of four grown children and is active in the Association for Retarded Citizens.

The following is an excerpt of an article from Exceptional Parent, Volume 17, No. 2, March, 1987. (Reprinted with permission from the author.)

Boy Scouts, Girl Scouts, Campfire, and similar groups for youth offer excellent opportunities for children with disabilities to participate in recreational activities with those who are not disabled. Often, in larger communities, separate units are established to accommodate those with disabilities. This is a story of what can happen when integration occurs. It is also the story of what happens when a person with disabilities speaks for himself.

On April 21, 1986, Tim Fredericks was awarded the rank of Eagle Scout in Troop 161, a regular Boy Scout Troop of Philomath, Ore. (population: 2,500). One of the guest speakers at that ceremony had the following to say:

> "The State of Oregon spends millions of dollars annually to maintain those with disabilities in separate work facilities and in institutions.
>
> This community demonstrates how to integrate someone who is disabled into the mainstream of its society. Troop 161 could be a model for all other Boy Scout troops."

Choosing a Project

Tim Fredericks has Down syndrome. Yet his entire Boy Scout career of eleven years was spent in regular Cub Scout dens and a regular Boy Scout troop.

Tim met the requirements for the twenty-one merit badges necessary for the Eagle rank, but most important was his Eagle project, which he independently chose. His desire was to speak at school assemblies and tell other students what it is like to be disabled. Eagle projects must be approved by the Boy Scout district. In this case, the district was quite enthusiastic about the project's possibilities and wrote an encouraging response to Tim's request. The next step for Tim was to prepare the speech and write letters to school principals requesting the opportunity to speak.

Tim reads at about the third-grade level, and he prints anything he writes. He can neither read nor write cursive lettering, nor does he adequately compose and write at the same time. Therefore, Tim and his family developed a technique for all of his correspondence. Tim dictates what he wants to say while one of his parents prints his words. Tim then copies the dictated material. Tim's dictation over the years has become quite fluent, and he does not tolerate any editing of his ideas. He occasionally tolerates a suggested word or phrase change.

Writing a speech was more complex, however. Tim had many things he wanted to say to students who are not disabled and had no difficulty dictating these ideas over a period of two weeks. I suggested organizing the speech by subjects: school, work, friends, etc. Tim agreed, and all the ideas for each subject were grouped. Tim then added and deleted. Finally, a speech emerged.

The speech Tim gave was initially planned to be given to two or three high schools and junior high schools or elementary schools in the immediate area. He ended up by speaking twenty-seven times to more than 2,500 people. The speech he gave follows:

Tim's Speech

My name is Tim Fredericks. I am handicapped because I have Down syndrome. I was born with Down syndrome. Down syndrome people have an extra chromosome. Nobody knows why we have this extra chromosome. All of you have forty-six chromosomes. I have forty-seven. Would any of you like my extra chromosome? I would be glad to give it to you if I could.

I would like to tell you what it is like to be retarded. I am doing this so that you might be able to understand people like me.

School is a good place to learn, but I don't really like to go to school. I am a slow learner. I have a hard time spelling. Some of your teachers tell me that you have a hard time spelling, and you don't have my problem. I have trouble reading. Everyone tells me that I read about the fifth grade level. I hate to write letters and to write in my diary because it is hard for me to write.

After I graduate from school, I hope to live in an apartment with a good friend. I also hope to have two or three part-time jobs. I have two now that I get paid for. I work at Ark Animal Hospital every morning for two hours. I have to be there at 7:15. I work at Vandehey's Cabinet Shop three afternoons a week. I have been working now for more than a year at both jobs.

I do chores at home. I have to take care of all the animals, twelve chickens, three cats, a dog, three goldfish and a horse. That's a lot of mouths to feed.

I also help my Dad cut wood. I take care of my own room, and I help my Mom vacuum. She says I do a better job than she does. And she is right!

I love music, but I like hard rock best, but my Mom doesn't.

I have a hard time explaining how I feel, but I feel the same way you do.

The hardest thing for me is when people make fun of me or ignore me. For instance, I went to a dance a few weeks ago, and no girl would dance with me. Can you imagine how you would feel if that happened to you? Well, I feel the same way.

Kids on the bus used to make fun of me. That used to make me mad.

I have a girlfriend, but she goes to a different school than I do. I don't get to see her too often. She is handicapped too. I have other handicapped friends, but my best friends are Chris and Mark Weaver. They have been my friends for five years. I think they really like me, and I like them.

I feel good when people talk to me or are friendly to me. That's one of the things I like about Boy Scouts. The boys accept me as I am. They know I am handicapped, but it doesn't make any difference. I am a scout just like them. It takes me longer, and I have to work a little harder to get my merit badges, but I get them done.

That's one of the reasons I am here. I am trying to be an Eagle Scout. I only have three more merit badges to go. My Eagle Scout project was to tell you about myself. I hope I have done that. I want to thank the principal, the staff, and students for letting me come and talk to you.

If anyone would like to ask any questions, I'll try to answer them, but if I can't, my Dad is here, and he can help me.

The Students' Reaction

And what was the reaction of the students? When he gave his speech to the school assembly of his own high school, the introduction by the principal was brief and noninformative: "Tim Fredericks is going to tell us something about his Eagle Scout project."

Tim stood before the student body of 400 with the microphone a little too close to his mouth so that his voice boomed throughout the auditorium. This was Tim's first speech, and so we as parents had little idea of what the reaction might be. The speech lasted approximately ten minutes. When he finished speaking, there was a spontaneous cheer from the student body, and all were on their feet applauding and cheering. Teachers were wiping tears from their eyes. One teacher said to Tim's mother, "We all needed that. Thank you."

Tim had been integrated into the high school for four years and had many friends who were not disabled, but the majority of the student body merely accepted him without really knowing much about him. However, after giving the speech, Tim said that everyone spoke to him.

Speaking to Elementary Students

It was fascinating to watch Tim give this speech, which was slightly edited from the one above, to elementary school students. The usual scenario went as follows: Tim would be introduced to approximately 100 students who would be sitting around the floor in a library or in some other general meeting room in the school. He would give his speech. At the conclusion of the speech, when he asked for questions, there would be a few seconds of silence followed by one hand of a student braver than the others. The question was usually quite simple. "What is your favorite music?" Tim would answer, and two more hands would be raised. Twenty minutes later, after a continuous give and take during a question period, half the student body would have their hands raised wanting to know more about Tim and what it is like to be handicapped.

We do not know the full effect Tim has had by being his own spokesperson, although many people have shared their personal reactions with us. We do believe he has made many more students and adults aware of the competencies that people with disabilities can have, and that those with disabilities are, first and foremost, people.

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Suggestions for Parents: Helping Children Achieve Self-Determination

Being aware of the significance of self-esteem and decision-making and problem-solving skills in a young person's overall development does not necessarily mean that parents and professionals know how to how to encourage the growth of these skills. The following suggestions for how parents and others can help children and young adults with disabilities develop a sense of self-worth and self-sufficiency have been developed from readings in disability literature and from conversations with individuals with disabilities.

- Treat your child with a disability as a capable human being by encouraging and supporting his or her efforts to explore, take healthy risks, and try out new situations.
- Provide opportunities for self-awareness by focusing on your child's strengths and the qualities that make him or her special and unique.
- Let your child know that you enjoy spending time with him or her. Try to really listen when your child shares thoughts and experiences with you.
- Share your family stories, histories, and traditions with your child to help the child understand that he or she is a member of a family circle, with a permanent place in the larger scheme of things.
- Provide opportunities for interaction with others of different ages and backgrounds to help your child develop social confidence.
- Help your child experience success by encouraging him or her to build on known strengths and abilities.
- Acknowledge your child's efforts toward a goal, not just the final product or accomplishment.
- Have realistic expectations; don't expect so much that your child is set up for failure or frustration, or so little that you communicate a lack of faith.
- Let your child take responsibility for his or her own actions.
- Acknowledge your child's presence. Include your child in discussions with family and friends. Don't interfere unnecessarily to answer questions that were directed at the child.

- Give your child a chance to grow into a unique adult. Avoid using labels such as "shy," "lazy," or "clumsy" to describe your child.
- Respect your child's need for privacy and time alone. Don't intrude unless it is absolutely necessary.
- Promote your child's assertive (not aggressive) behavior as well as respect for others. Being assertive is an excellent way for your child to avoid being exploited or taken advantage of.
- Encourage your child to practice and use basic coping statements to handle difficult emotions, such as anger, jealousy, or fear, but by all means, encourage their expression. (An example of a coping statement might be: "I can do this. I'll be just fine." or, "I really feel upset, but I need to stay calm.")
- Acknowledge your own sense of self-worth, when appropriate. Your healthy self-image will be a good model for your child.

There are many resources available to help parents understand their role in helping their child with disabilities learn to achieve self-determination. Many such resources are listed at the end of this *Transition Summary*.

As you face your responsibility as a parent, a teacher, or a professional in helping a child with disabilities achieve self-sufficiency, remember that learning to be independent is a difficult task for all young adults. Likewise, it is sometimes difficult to earnestly encourage a child's independence: letting go is one of the most difficult tasks that parents face. What is important to realize is that all children, regardless of their strengths or weaknesses, have to try many times -- and sometimes fail -- before they can gain the self-assurance and sense of personal worth that comes with adulthood.

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Magazines For and About People with Disabilities.

Disability Rag, Box 145, Louisville KY 40201. Phone (502) 459- 5343 [TDY]. (A bi-monthly publication written by people with disabilities that covers the whole spectrum of disability rights.)

Legislation to Watch: The Disability Rights Bill.

As of this publication, this bill is pending before the House and Senate. It is sponsored by Congressmen Major Owens (D-N.Y.), James Jeffords (R-Vt.), Tony Coelho (D-Calif), and Silvio Conte (R- Mass.), and Senators Tom Harkin (D-Iowa), and Lowell Weicker (R-Conn.).

If passed, this bill would give individuals with handicaps the same rights afforded the disadvantaged and other minority groups under other existing Civil Rights legislation. For more information, contact Bob Tate at (202) 226-7532.

ORGANIZATIONS

American Association of Disability Communicators, c/o National Organization on Disability, Suite 600, 910 16th St., N.W., Washington, DC 20006. (An organization concerned with disability issues and seeking improvements in disability communications. Publishes a quarterly newsletter, the AADC News.)

The Beach Center on Families and Disability. Contact Gary Brunk, The Beach Center on Families and Disability, The University of Kansas, Lawrence, KS 66045. Phone (913) 864-4950. (A federally funded national rehabilitation research and training center on families and disabilities. The purpose of the center's research, programs, and training is to advance the rights of people with disabilities at every age as well as the members of their families to have enduring and supporting relationships with each other in their homes, neighborhoods, and communities.)

The Disability Rights Center, 1346 Connecticut Avenue, N.W., Suite 1124, Washington, DC 20036. Phone (202) 223-3304. (A center established to advocate for the rights of all persons with disabilities. Publishes information on understanding disability, employment discrimination, and other topics. Write the center for a price list for the publications.)

The Disability Rights Education and Defense Fund (DREDF), 1616 P St., N.W., Suite 100, Washington, DC 20036. Phone (202) 328-5185 Voice or TDD. (A national nonprofit organization run primarily by people with disabilities. Offers information on the civil rights of people with disabilities. Publishes *Disability Rights Review*, a quarterly newsletter.) The national office is located at 2212 6th St., Berkeley, CA 94710.

Mainstream, Inc. , 1030 15th St., N.W., Suite 1010, Washington, DC 20005. Phone (202) 898-0202. (A National non-profit organization that works with corporations, state, local, and federal government, educators, and rehabilitation professionals to move persons with disabilities into the workplace. The organization sponsors conferences and disseminates publications on employment.)

National Self-Help Clearinghouse, 25 West 43rd, Room 620, New York, NY, 10036. Phone (212) 642-2944 (A national information and referral service for people seeking or wanting to create a self-help group.)

People First International, P.O. Box 12642, Salem, OR 97309. Phone (503) 378-5136. (A self-advocacy group of teenagers and adults with developmental disabilities. People First exists in 20 states. Addresses and phone numbers of existing offices available through the Salem, OR address.

The Research and Training Center on Independent Living, BCR-3111 Haworth Hall, University of Kansas, Lawrence, KS 66045-2930. Phone (913) 864-4095 [Voice/TDD]. (A center established to help people with disabilities live more independent lives. Conducts research on issues in the independent living field. Produces materials from studies, research, and training activities.)

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